



ITALIAN HD ASSOCIATION ROME - ITALY

# A.I.C.H.



ASSOCIAZIONE ITALIANA COREA DI HUNTINGTON ROMA ONLUS

**THE ASSOCIATION**

Established in 1989, the HD association of Rome (AICH-ROMA ONLUS) is a national lay organization concerning individuals and families affected by Huntington's disease. It has approximately 700 associates and 15 volunteers including several professionals, researchers and clinicians. AICH-Rome is also the referring point of about 400 between patients, at risk family members and presymptomatic gene-carriers from all the Country.

**INFORMATION AND EDUCATION**



AICH-Rome has held several meetings and seminars for families and professionals on various topics: research developments, social rights of patients and families, drug therapies, rehabilitative approach to HD;

-Upon joint request of AICH Rome and AICH Milan a multidisciplinary panel of experts about HD was set up in 2007 in order to publish a manual in Italian for Neurologists providing recommendations for the best management of HD patients.



**FUNDRAISING**

-AICH-Rome usually raise funds through association fees, private donations, artistic performances and social events (football matches and theatre performances)

**www.aichroma.com**

plays a relevant role: it's an interactive website frequently updated, providing information on HD and about association initiatives, answers to faq,



a free of charge weekly

newsletter to subscribers (near 600 individuals are enrolled), an essential bibliography for professionals and students, archives with past issues of the association newsletter since the beginning, links to the main websites concerning HD associations in the world, and tips from handicap world.

The web site also offers a permanent discussion forum open to people involved in HD as well as to professionals interested in the disease. Genetic Counselling are also provided as well as Legal and Social advice. - A quarterly newsletter has been published since 1994, reporting original articles on HD (research and assistance) and association news and activities;

- Since 2004, thanks to the precious work of Wanda Danzi, we started a national informative campaign on hd aimed to increase knowledge of the disease in the whole society. With collaboration of "testimonials" from the world of arts and sport we started a press campaign including media as tv and radio, a tv spot and calendars with testimonials' photos were produced.

**FAMILY AND PATIENT SUPPORT**

A Medical-Psychological Integrated Outpatients Service for HD at Policlinico "A Gemelli" is active once a month since 15 years. The booking service is provided by AICH-Rome ONLUS. A second outpatients service was established in 2006 at the Policlinico S.Andrea with two neurologists offering on voluntary basis either control visits at the association venue itself.



**SOCIAL ACTIVITIES**

Thanks to the executive officer of AICH-ROMA ONLUS the Holiday program was launched involving patients and relatives in pleasant tours all over the Country.



**RESEARCH**

AICH-Rome onlus collaborates with main national Institution such as the National Research Council to specific scientific research projects



**BOARD MEMBERS:**  
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